

# **Immunization Registry Moderator's Guide FINAL**

**NOTE:**

- All participants are parents of a child who has not reached his or her sixth birthday
- Some groups will have participants with a high school diploma or less
- Some groups will have participants with education beyond a high school diploma

## **OPENING COMMENTS AND INTRODUCTION (10 mins.)**

- Welcome, thank participants for agreeing to come
- Explain what a focus group is, purpose of the group (to obtain different ideas people have about immunization), process and ground rules for discussion
- Encourage participants to speak freely, not seeking a consensus
- Disclose recording devices and observers (members of the research team); assure confidentiality

**Let's begin by introducing ourselves. You probably remember from the invitation to participate, you were asked some questions about your children. I'd like to continue with that theme. Tell us your first name, the ages of your children and some of the activities you enjoy with them.**

## **Section 1**

### **GENERAL IMMUNIZATION AND HEALTH CARE (15 mins.)**

#### **I. Prevention ( 5 mins.)**

**One thing that we can all agree on is that everyone wants to keep their children from getting diseases. What are some DISEASES that you as parents are most concerned about?** [NOTE: Moderator should focus participants on the worse diseases (not the common cold, for example).]

#### **II. Immunization ( 10 mins.)**

**To keep your children from getting the diseases we just discussed; there are different things parents can do. We're going to talk specifically about immunization and vaccines.** [NOTE: Moderator will let the participants know that for the purpose of the discussion it is OK to use "immunization" and "vaccine" interchangeably.] **As parents of young children you are probably aware that there is a recommended schedule of vaccines for children. Most parents choose to follow the recommended immunization schedule. I know some parents have personal reasons for deciding not to follow the schedule. Your opinions and reasons for not immunizing are also very important to me and I want to hear your views very much. Remember that we are here to discuss all the different ideas people have about immunization. I want to hear from everyone.**

- a. Let's talk about REASONS SOME PEOPLE GET VACCINATIONS and REASONS SOME PEOPLE DO NOT. Let's start with reasons some people get vaccinations.**

[Note to moderator: Stagger the introduction of these issues from group to group, e.g., for next group, start with reasons some people do not get vaccinations.]

- b. Now, what are some reasons for not vaccinating?**
- c. How do you know when it is TIME for your child to get a vaccine?**

[NOTE: Moderator will hold off as long as possible before mentioning any of the

issues below. Will let the participants list as many as they can before any probes are offered.]

**Probe for:**   --Reminder card from doctor's office of clinic  
                  --Personal records (immunization record card)  
                  --Reminder from school or daycare

**d. What ways can you think of that would make it EASIER FOR YOU TO KEEP TRACK of what vaccines your child has had or will need in the future?**

## Section 2 IMMUNIZATION REGISTRIES ( 55 mins.)

### I. GENERAL BACKGROUND ( 15 mins.)

For the rest of our discussion, I would like for us to talk about something called an immunization registry. Let me begin by telling you some very basic information. Public health officials want to make the immunization process as easy as possible for both parents and health care providers. One way to do that is through immunization registries. Immunization registries contain information about a child's immunization history. The **PURPOSE** of immunization registries is to allow health care providers to have easy access to information about a child's immunization history. The **GENERAL PUBLIC DOES NOT HAVE ACCESS** to the information. There is **NO NATIONAL REGISTRY** where all the records are kept in a single place; however, each state or area **MAY BE LINKED BY COMPUTER** to other states or areas.

**There are a few BASIC THINGS a registry can do:** (The moderator will provide these on a handout AND READ IT ALOUD ALSO.)

- Allows your child's complete immunization history to be available to all health care providers your child may see in the area you live
- Tells a doctor which immunizations your child already has had and which ones are due
- Can produce a copy of your child's immunization history for you if you need one for your child to enter school or day care or go to camp
- Helps doctors provide a reminder to you of when an immunization is due for your child or if one has been missed
- If you move to a new area, can transfer your child's immunization information to a new health care provider and registry so that all of your child's immunizations can be combined into a single list

**I will be giving you more details about registries in a short while, but first, based on this basic information, tell me what your INITIAL REACTIONS are to the idea of a registry.**

**Probe--**

- What appeals to you about a registry?

- What concerns come immediately to mind?
- What further questions would you want to have answered?
- Had any of you heard of an immunization registry prior to this discussion?
- How did you learn about them?
- Does anyone in the group have a child who is in an immunization registry?

## **II. CONTENT OF THE REGISTRIES (15 mins.)**

**Now let me tell you a bit more about what information is actually in a registry.** (Moderator will distribute handouts with list of items and read them off as well. If someone asks, the moderator can clarify that a lot number refers to the batch that the vaccine came from.)

*The following information is on the handout:*

**The system keeps track of the following information for each immunization that your child has received:**

- Type of vaccine (e.g., polio, MMR)
- Date the vaccine was administered
- Company that made the vaccine
- The lot number of the vaccine

**It can also contain information such as:**

- Child's full name
- Child's date of birth
- Child's gender
- Mother's full name (including maiden name)

**a. What is your INITIAL REACTION to seeing the TYPE OF INFORMATION typically included in an immunization registry?**

**Probe for:** --What information are you MOST COMFORTABLE with?  
WHY?

--What information are you MOST UNCOMFORTABLE  
with? WHY?

**b. HOW WOULD YOU FEEL if your HOME ADDRESS and PHONE  
NUMBER were included in the registry?**

**c. HOW WOULD YOU FEEL if your SOCIAL SECURITY NUMBER OR  
THAT OF YOUR CHILD were included in the registry?**

**d. HOW WOULD YOU FEEL if you were ALSO ENROLLED in a  
PROGRAM like WIC (Women, Infants and Children) or MEDICAID and  
your WIC number or Medicaid NUMBER WAS IN THE REGISTRY?**

### **III. ACCESS ( 10 mins.)**

**Now let's talk specifically about WHO IS GOING TO HAVE ACCESS to  
that information in the registry.**

**a. WHO SHOULD have access?**

--Are there any **circumstances** in which **the people you just mentioned** should  
**NOT** have access?

**b. WHO SHOULD NOT have access?**

--Are there any **circumstances** in which **the people you just mentioned**  
**SHOULD** have access?

**c. How would you feel if you knew that the registry might BE LINKED BY  
COMPUTER TO OTHER SYSTEMS that have information about health?  
For example, the WIC system, Medicaid system, or a system that tracks  
screening for lead poisoning?** [Note to moderator: This question is different from  
the previous one about WIC and Medicaid in that before we were only talking

about having the IDENTIFIERS included in the immunization registry. Now we are talking about a LINK between systems.]

[NOTE: Moderator will probe for the following groups or individuals having access if they are not mentioned by anyone and if time permits.]

**Probe for-**     --schools  
                  --day care administrators  
                  --researchers  
                  --health insurers

#### **IV. CONSENT AND INCLUSION (20 mins.)**

**Let's talk about how information GETS INTO THE REGISTRY. States have DIFFERENT LAWS and POLICIES regarding the SHARING OF INFORMATION and PARTICIPATION in immunization registries. I want to describe for you the MOST COMMON WAYS that states deal with these issues.**

- **In MOST states, a child's immunization information is NOT INCLUDED in a registry UNTIL PARENTS have been NOTIFIED that they have the OPPORTUNITY to decide if the information should be included. IF PARENTS DO NOT WANT the information included, then THEY MUST TAKE A SPECIFIC ACTION such as telling the appropriate person or signing a form. This is called "OPTING OUT" of the registry. If PARENTS DON NOT RESPOND to the notification, then IT IS ASSUMED that it is OK with the parents to go ahead and include the child's immunization information.**
- **In some states, ALL PARENTS MUST GIVE EXPLICIT PERMISSION before a child's immunization information is included in the registry. Typically, THERE IS A FORM that they must SIGN. This is called "CONSENT." This is DIFFERENT from THE OTHER LAW I told you about. In this situation, the people who maintain the registry are NOT ALLOWED TO ASSUME that the parents want the information included unless the parents directly say it is OK.**
- **In a few states, the LAW REQUIRES that the INFORMATION BE INCLUDED in a registry. PARENTS DO NOT HAVE THE CHANCE TO**

**GIVE THEIR CONSENT for their child to be in the registry. Also, parents do not have the option of having a child's information taken out of the registry.**

**Let's talk about how you feel about each of these options.**

**1) Assume you live in a state where your child's immunization information will be entered in the registry unless you take action not to have the information included. Remember that I called to this type of action "opting out." How would you feel about this policy?**

**Probe reasons for responses:**

--For those that want the chance to opt out, why?

--Are there concerns about the assumption that will be made about the parents' wishes if they --don't respond to the notification?

--What are the advantages/disadvantages for the overall health of the public?

**2) Assume you live in a state where your child's immunization information will not be entered in the registry unless you first give written or verbal permission. Remember that I called to this type of action "consent." How would you feel about this policy ?**

**Probe for reasons for responses:**

--Why is consent important or not important?

--What are the advantages/disadvantages for the overall health of the public?

**3.) Assume you live in a state where your child's immunization information will be entered in the registry automatically, and there is no opportunity to opt out or give consent. How would you feel about this policy?**

**Probe for reasons for responses:**



What are the advantages/disadvantages for the overall health of the public?

### Section 3 WRAP UP AND CLOSING ( 15 mins.)

**We've talked about what an immunization registry is, what information is in it, who has access, and how the information gets there. Considering all that we have talked about tonight tell me:**

**I. What are the most important BENEFITS you see?**

[Note to moderator: If the following issues have not been mentioned as benefits by anyone in the group up to this point, then bring them up to see how the participants react. Don't mention them until they have ample opportunity to mention them spontaneously.]

**Probe for:**

--reduces the chance of a child being immunized multiple times for the same disease due to lost records, moving, switching health care providers, etc.

--ensures that a child who has a particular medical is not given a vaccine that could be potentially harmful

**II. What are your greatest CONCERNS or what are the biggest RISKS you see?**

[Note to moderator: If the following issues have not been mentioned as concerns by anyone in the group up to this point, then bring them up to see how the participants react. Don't mention them until they have ample opportunity to mention them spontaneously.]

**Probe for-**

- law enforcement (immigration and naturalization issues)
- government having too much information
- tracking of children
- denial of health benefits
- denied entry to day care and school

--custodial issues (e.g., ex-spouse obtaining address/viewing records)

**III. How would your feelings toward immunization registries be affected by your healthcare provider's opinion about them?**

**We are just about out of time now. I am going to go out and check to see if your envelopes are ready.**

**While I am gone, I am going to ask that you use the paper and pen to answer this question:**

**Q: If there were one thing you could say to the people who are responsible for how the registry system works, what would that be?**

**I will be right back.** (Moderator steps out of room, checks in with observers for any additional questions)

Upon return, moderator will:

1. Review answers to question about what participants would say to those responsible for registry system;
2. Pose any questions from observers;
3. Thank observers for participating; and
4. Officially end the group.

**TOTAL PLANNED TIME: 1 hour and 45 minutes**